

River of Words, Raft of Our Conjoined Neurologies

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*I looked at my hands, to see if I was the same person now that I was free.
There was such a glory over everything; the sun came like gold
through the trees . . . and I felt like I was in heaven.*

*If you hear the dogs, keep going. If you see the torches in the woods,
keep going. Don't ever stop. Keep going. If you want a taste
of freedom, keep going.*

—Harriet Tubman

In the eighth grade, my son, DJ, who is autistic and who uses a text-to-voice synthesizer to communicate, became so distraught while learning about Harriet Tubman and a little Polish boy whom the Germans murdered that he couldn't continue reading. His breathing was heavy; his eyes had glazed over. His heart pounded in the narrow cage of his chest. In response to his ninth-grade English teacher's question, "What are your strengths as a reader?" he replied, "I feel characters' feelings." He then added, "Dread very scary books and wish I took breathing easy mom to class to create more security."

In the sterile language of literary critics, DJ can be said to have identified with these historical figures. Having been abandoned by his birth mother at the age of three and subjected to constant abuse in foster care, he experienced a similar barbarism. In the case of Tubman, the identification was particularly intense. DJ saw in this leader of the Underground Railroad what he calls "political freedom fighting," and he imagined working on behalf of his

“people”: namely, those with autism who cannot speak and who have been presumed—wrongly—to be retarded.

Consider what he wrote about Moses, as Tubman was called, a few days after first learning about her. The process of composition was no less physiologically agitating than reading had been; indeed, DJ periodically let loose with shrieks and head-banging. So that you understand the first line of the piece, let me say that “Breaking the Barriers” is the official motto of a disability rights group whose website features a speech by my son. Let me also say that “Frees” refers to those who don’t have autism and, thus, who claim a privileged position in society.

ESTIMATING HARRIET TUBMAN RESPECTFULLY

If we’re breaking the barriers, great freedom fearfully awaits.
 Harriet realized, until freedom treated her people with respect,
 her intestines seemed unsettled, her heart beat resentfully, and her
 fear never disappeared. The challenges she faced each day were far
 greater than anything you and your people have ever endured;
 breathing resentful air, great very hard breaths, undermines
 heartfelt feelings and deeply affects the western world. Pedestals
 rest on hurt, estimated dressed not great human beings deserted
 by frees. I heartily entreat you to help my unfree, treated responsibly,
 great, hip, jumping self to walk the trail. You kind, responded easy
 breathing frees don’t understand how terrifying seemingly fresh
 freedom is.

It should be clear that a term like “identification” can’t convey this sort of readerly cathexis. We might instead speak of “intimate history” or “relational time” and note just how visceral the engagement seems. DJ feels Tubman’s “unsettled intestines,” “very hard breaths,” and “racing heart” because his own walk down freedom’s trail, as the only fully included student with classical autism in Iowa, has been equivalently “terrifying.” As he morphs into her, so she morphs into him: a fellow traveler in need of respectful estimation. I’ve come to think that my son has borrowed the language of educational assessment and deployed it ironically. In the chapter he wrote for my book *Reasonable People*, he remarked of his former special-ed instructors, “No one was assessing me as sweet.” It’s as if the flawed judgment of ability (and thus

of human worth) at the hands of the powerful has become the primary lens through which he views experience.

His frustration with the dominant majority can be seen in a piece from the fifth grade that he wrote for an Elk's Club writing contest:

The great United States of America is breathtakingly not free.
 Equality is not as sacred because not everyone has access to it.
 Freedom is not as available as many people think. First, free
 people treat my people, very smart people who type to communicate,
 as mindless. Second, they underestimate us as very bad instead of
 reaching out to us. The creators of everyone's very important
 Declaration of Independence wasted their breath.

Needless to say, DJ didn't win the contest, as the Elks were hoping for something a bit more positive. I frankly love the repetition of "breath"—the way the paragraph begins and ends with this word. It's as if DJ had condensed the primary physical symptom of his anxiety—heavy breathing—into a political modifier. My son was demanding his place in America. I remember taking note of the signature trope, which rediscovers the body as a way of reviving the cliché, and picturing democracy itself in respiratory distress.

The concern with breathing shows up repeatedly in his writings, particularly in the sixth grade when he composed the final chapter of *Reasonable People*. In that chapter he includes a letter he wrote to his middle-school principal after a meltdown threatened to have him expelled: "It's very important to me to be at Grinnell Middle School. . . . I very much value teachers who give nice instructions breathing easily." "You ignored the resentment in my young breath," he says, grateful for another chance to prove himself. "As long as I treat people resentfully, I will miss out on telling people that kids who don't talk deserve to be in a real school." "Respect for others," he concedes, "is important. Respect for underestimated kids is important, too, because they read and resent testing that mistakenly identifies them as retarded." At the end of the chapter, punning off of the book's title, he declares, "Reasonable people promote very, very easy breathing."

While there's no doubt that the fight-or-flight impulses of post-traumatic stress disorder have contributed to DJ's anxiety, the experience of inclusion and the literacy at its core have, paradoxically, as well. Learning to read

empowered him to become a disability rights activist, and yet it also awakened him to the story of his early childhood and the often negative meaning of his difference. Like a boy learning to lift himself out of the deep end of a pool, he emerged from the sensory murk of an alternative neurology only to be clobbered by the sunlit clarity of what had been wrought upon him. He found himself running to, and from, words—as if they were, interchangeably, a policeman and an assailant. Reading became both a form of survival as he bonded with characters like himself and a kind of traumatic channeling of their injuries.

Utterly alone as a small child, as a 12- and 13-year-old he demanded the constant company of his parents, especially while doing work for English or history class, his hand often resting in one of ours as we read with him a particular assignment. At times we wondered if he would survive literacy, which he had achieved in the fourth and fifth grades, long after most schoolchildren, and then mastered, rocketing forward—to the point that he would graduate from high school with a straight “A” average and would be admitted to Oberlin College as its first nonspeaking student with autism. During these middle school years, a tense narrative would invariably elicit a full-blown flashback and the ashen visage of the war veteran. Sometimes we’d have to sit on him to prevent self-injury, his legs and arms flailing.

Of course, in many ways, DJ’s emergence into literacy was no different from a typical child’s, however belatedly it occurred. In “Children Selecting Books in a Library,” the poet Randall Jarrell captures the mythic danger of this unsuspecting skill:

With beasts and gods, above, the wall is bright.
 The child’s head, bent to the book-colored shelves,
 Is slow and sidelong and food-gathering,
 Moving in blind grace . . . yet from the mural, Care,
 The grey-eyed one, fishing the morning mist,
 Seizes the baby hero by the hair
 And whispers, in the tongue of gods and children,
 Words of a doom as ecumenical as dawn
 But blanched like dawn, with dew.

Drawn like an animal to a baited trap, the child feels the spring-loaded words come down upon him. And yet, this violence, this “doom,” seems strangely pleasurable; it is the force of what I previously called identification—and what might as well be thought of as a kind of compassion. “Read meanwhile . . . hunt among the shelves, as dogs do, grasses, /” Jarrell writes, “. . . we live/by trading another’s sorrow for our own.” As the child grows up, whatever was unnerving about this activity falls away.

Not so for classical autists, who, even after they’ve been reading for some time, cannot trade sorrow as nonchalantly as their counterparts. Though you wouldn’t know it from prevailing stereotypes, classical autists *do* experience this emotion, and quite intensely. In fact, it often overwhelms them. Stephen Shore, an autistic writer, speaks of “fusing” with another’s suffering, whether real or imagined—of being so attuned to the pain that it becomes his own. Rita Rubin has told me that her daughter Sue, star of the Academy Award-nominated *Autism Is a World*, watched the film *Malcolm X* from another room—the violence and oppression were just too much for her. Neurotypical engagement seems, in contrast, to be much less full or dynamic; it involves moving toward the sufferer-who-is-not-me while vigilantly preserving a sense of separateness. My son’s autism, I came to believe, was acting as a second accelerant, igniting the timber frame of narrative and turning it into a four-alarm fire. Along with his trauma, it prevented a more stable or removed reading experience.

There isn’t space—or available research—to account for this fire adequately. It seems to have something to do with the phenomenon of cerebral lateralization. When neurotypical children learn to speak, a shift in dominance occurs from the right to the left hemisphere. When they learn to read, this shift deepens. In addition to being responsible for nearly all of the literary aspects of language, the right hemisphere plays a key role in emotion (thus empathy) and in spiritual feeling. The left hemisphere, on the other hand, is responsible for the “linear reasoning functions of language,” such as grammar and word-finding. Here, too, reside logical and linear algorithmic processing, as well as measurement skills.

The left hemisphere gives us our sense of time and what Jill Bolte Taylor calls our “personal physical boundaries”—something, interestingly enough, that classical autists have great trouble with. (So frequently does he “lose [his]

body” that Tito Mukhopadhyay, perhaps the world’s most famous classical autist, has remarked, “I flap to know that I have arms.”) As Bolte Taylor says of stroke victims and Tibetan meditators alike, “When the [posterior parietal gyrus of the left hemisphere] is inhibited or displays decreased input from our sensory systems, we lose sight of where we begin and end relative to the space around us.” Intensity of spiritual feeling, that sense of oneness that many have experienced, can be induced, Bolte Taylor tells us, through the practiced suppression of ordinary hemispheric dominance.

Whereas the literate neurotypical moves into adulthood with an inhibited right hemisphere, the literate classical autist appears to do just the opposite. He doesn’t undergo a shift in dominance, or if he does, it is much less dramatic. He seems to retain not only many of the young neurotypical’s cognitive proclivities—including an emphasis on the concrete over the abstract, a fondness for simile and metaphor, and a belief in animism (or the sense that the universe is fundamentally interconnected and alive)—but also that child’s comparatively unchecked emotion. In some ways, the classical autist is akin to the poet who has learned, like the Tibetan meditators I just referenced, to inhibit his left hemisphere—in this case, to encourage figures of speech to spill over the levees of customary perception and language use—or who lives with a psychiatric condition that accomplishes the same thing. In “Poetry as Right-hemispheric Language,” Julie Kane argues that “many, if not most, poets . . . experience temporary elevations of mood (hypomania) accompanied by a reversal of normal laterality for language.” It is the sustained reversal of this laterality that perhaps accounts for the metaphor-laden prose of many who type to communicate. To put it too simply, the classical autist seems to read with the intensity of a small child, while otherwise manifesting a conventional, if not superior, maturity.

Call this autist, if not an ideal reader, then a most invested one, bringing his boundaryless empathy (which could well be linked to his boundaryless body) and analogical talent to the project of literature. But at what cost? Might this form of literacy be tempered, if only partially?

By the time tenth grade came around, I devoted myself to making reading more manageable for DJ. While he loved encountering great fictional and historical heroes, it took too much out of him. He was like a kid with a weak stomach who’s addicted to roller coasters. Or a cast-iron stove that needed a dampener, burning so hot it shook and turned an ominous red. I knew that

the key text in his multigenre, multitrade tradition literature class would be *The Adventures of Huckleberry Finn*, which famously presents an adopted—and abused—child protagonist. “Pap got too handy with his hick’ry, and I couldn’t stand it. I was all over welts,” Huck tells us at the beginning. As if this weren’t worrisome enough, the novel explores the issue of slavery, subjecting Jim to the worst sort of comic shenanigans. DJ might resent the lighthearted approach or ignore it all together, “feeling,” in his word, the grave danger of a runaway slave.

I decided to create a ritual to cushion the impact: we’d do his reading for English in the master bedroom. A recent addition to our one-and-a-half-story Queen Anne home, the room has five skylights but no windows. With its sloping roof and picturesque purchase on the heavens, it feels as snug as a well-lit cave. Or a raft with a wigwam on it, “to get under in blazing weather and rainy, and to keep things dry,” as Huck says. I told DJ that the bed was our floating haven, and the novel our wide and meandering Mississippi. Whenever he’d get that ashen look on his face or threaten to bang his head, I’d declare in the best Missouri twang I could muster, “There aint no home like a raft, after all. Other places do seem so cramped up and smothery, but a raft don’t. You feel mighty free and easy and comfortable on a raft.”

I figured I’d encourage my son to allegorize the reading process itself, to dedicate his considerable imagination to becoming not Huck honey, but an exemplary reader, lighting out for the territory of crafted sentences and alternative values. I wanted him to feel at home in literature: to regard the current of a writer’s prose, to hear its swirling cadences—not as an escape from life, but as a beautiful refraction of it. “The sky looks ever so deep when you lay down on your back in the moonshine,” Huck notes, and lying on our backs in that comfortable queen-sized bed, we discovered a depth that could sustain us—an expanse of vision in, or under, which we could never feel “cramped up and smothery.”

Adoptive father and son, non-autistic writer and autistic high school student—what were these supine lumps but conjoined neurologies encountering the splendor of a classic book. As DJ met me in the space of appreciative analysis, so I met him in the space of uncontrollable cathexis. Long before I had acquainted myself with neurological research, I had frequently thought that writers, especially poets, spend their careers trying to get back to childhood—that sense of immediacy, of wonder, of complete engagement;

that moment when language is as bendable as taffy. Certainly Jarrell did so with his many poems from a child's perspective and his children's books. If right-hemispheric dominance is the scribbler's lost (or at best intermittently retrievable) Eden, then classical autists can be said to dwell continuously among the animals of creation. As the Bible puts it, "The wolf will live with the lamb, the leopard will lie down with the goat, the calf and the lion and the yearling together; and a little child will lead them." As important, their neurologies suggest not a pathological otherness, but an alternate, and indeed praiseworthy, human trajectory.

Years of literary reading and writing had, I knew, transformed my own brain, rendering it, like the brain of a taxi driver after much city driving, less neurotypical. As Eleanor Maguire of University College London has shown, the posterior hippocampus in taxi drivers is significantly enlarged, reflecting a need for enhanced memory and spatial navigation. A 2006 study showed that significant activation differences exist in the brains of poets and non-poets when reading poetry, proving once again that how we use our brains can very much affect their structure and function. On the page and in life, I was more metaphorical, more emotional, than I had been as a young man. Dare I say, and only half facetiously, a bit more autistic? Once, in a discussion of the autism spectrum, DJ remarked, "Hoping that fresh thinking, very nervous dad is autistic." Perhaps movement in the other direction, toward neurotypicality, was also possible, I thought. My son needed a future in words—words that didn't swamp the ark of his longing, driving him under and filling his lungs with dread.

My distancing strategy proved effective, if only because DJ had started saying that he wanted to be a writer, and because I frequently interrupted whatever book I was reading aloud to ask how a particular scene had been staged or how an image was resonating. "As the author," I'd say, "you're the one behind the magic. How's it done here?" I also encouraged DJ to be critical, to take Twain or any other writer to task for their questionable aesthetics or politics. By junior year, he could calmly critique fiction's use of suspense to "string the reader along." "Many people joyfully succumb to this form of entertainment," he wrote in a paper. "Having never experienced hopeless terror in their own lives and knowing that the author will ultimately resolve the tension, they enjoy reading books that terrify them." (Years before, he

had complained about my memoir, which tracks his evolving literacy through a series of verbatim exchanges, because it had turned his life into a kind of pleasure. “I resent these very hurtful conversations being easy reading for others,” he declared. Although he granted me permission to publish the memoir—“Kids need our help,” he reasoned—neither the content nor the way that it was typically consumed sat well with him.)

Don’t get me wrong: reading remained a real challenge. Trying to get through Jon Krakauer’s *Into Thin Air*, one of the assigned texts for senior year, may have been as difficult as the Everest descent the book so effectively describes. By the time Rob Hall speaks to his wife for the very last time, patched through on the satellite phone, low on oxygen, his hands and feet horrifically frostbitten, telling her, “Sleep well, my sweetheart. Please don’t worry too much,” DJ was screaming at the top of his own oxygen-depleted lungs. I, to be fair, wasn’t doing much better. Reading truly was like making it down that blizzard-effaced col: each sentence a step you didn’t think your feet could take. At one point, DJ typed out “foster care,” his analogical mind knitting together two experiences of extreme helplessness. How could I not recall what he had written about his years as a wordless and, in some sense, fingerless little boy: “When I lived in fear, I yearned to urge just one especially humane free gesture to tell someone, ‘Just hear me. I really need help?’” Imagine being so plagued by fine-motor impediments that you can’t even command your hands to act out what is happening to you.

There was simply no way to render this read a lazy river float, and yet DJ *did* get through it. Even more impressive, he got over it quickly. Was he maturing? Was that brain of his—O wonderful plastic thing!—actually becoming a bit more neurotypical, allowing the left hemispheric dampener to assert itself? All I knew for sure was that reading had become unambivalently important to him, as a paper he wrote at the end of his junior year shows. It begins like this:

Last Thursday night was the Academic Excellence Award ceremony at my school. I yearned to walk up on stage and shake the principal’s hand without flapping my arms, but I did not succeed. At first I felt disappointed, but when I saw my dad waving to me with a huge smile on my face, I felt proud. I looked great *and* autistic at the same time. I realized in my own life something I had begun to learn from the books I was reading: simply

conforming to the dominant culture is not always a worthy goal. In fact, real change is only possible when different thinkers free people to open their eyes to new ways of being.

Just after this paper, our curly-haired nonconformist wrote a personal essay about the challenges, both physiological and psychological, of his inclusion experience—what he called, invoking Tubman once again, “my reassessed as smart self’s walk down freedom’s trail.” He describes his sensory dislocations: losing functional hearing and sight, especially when anxious; needing the heaviest of backpacks to locate his body in space; having occasionally to jolt his senses by purposefully crashing to the ground. All of this he conveys while narrating a typical morning’s journey to school—his heart a flock of pigeons in his chest, freedom still a distant mirage. Up to the front doors and through the swirling mass of students in the halls, he moves—trying to reach, as he puts it, “dear Mr. Rudolph and the safe house of my Honors American Literature classroom.”